Nothing about LGBTI ageing or aged care without us

Catherine Barrett, Val’s Café. Sexual Health and Ageing Program. Australian Research Centre in Sex, Health and Society, La Trobe University. © 2015 Latrobe University. This presentation cannot be replicated in part or full without the explicit permission of La Trobe University.
Sexual Health & Ageing Program

Four domains
- Sexual expression
- Sexual assault
- STIs
- Val’s Café

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GOAL 5: LGBTI communities, including older LGBTI people, will be actively engaged in the planning, delivery and evaluation of ageing and aged care policies, programs and services.

5.2: (DoHA will) resource and support projects and approaches that seek to empower older LGBTI people as self-advocates and experts to be consulted about their own ageing and aged care needs and circumstances.
Consulting older LGBTI people

Research projects

- DoSS ACSIHAG funded
  - Dementia: Alzheimer’s Australia
  - Trans: Gender Centre, TransGender Victoria
  - Intersex: OII
  - Carers: Carers Australia
  - Workforce diversity

- beyondblue: discrimination/anxiety and depression
- Matrix Guild/Vintage Men: experiences of aged care
Consultation methods

- Interviews
  - Narrative analysis
  - Narrative based resources
  - Photographs
- Surveys
- Film
- Art based
- National LGBTI Ageing and Aged Care Conference (Melbourne 26th and 27th)
Key issues identified

1. Still LGBTI ….
2. Sexual orientation and gender identity may be more restricted by the values and beliefs of families of origin and service providers than dementia itself
3. Older LGBTI people may delay/avoid accessing services because they fear discrimination
4. Older LGBTI people may rely heavily on intimate partners
5. Absence of healthy ageing pathways for trans and intersex people
6. Importance of Advance Care Planning/Guardians
Old age – a new frontier

**Early years**
- Pervasive discrimination
- Imprisonment
- ‘Hiding’
- Forced ‘cures’
- Family conflict
- Low expectations of others
- Reframing discrimination

**Middle years**
- Creating safe spaces where identities were affirmed
- Deciding who enters ‘my space’
- Making life work

**Old age**
- Reduced autonomy
- Social isolation
- Reliance on partners
- Re-encounters with family of origin
- Fear of discrimination – don’t make a fuss

valscafe.org.au
Reflections on the process:
Narrative plots
and why they matter
Thick narrative plots …

The importance of a plot:
- A series of events that make up a story
- Events are drawn together into a whole by means of a plot
- The plot is the structure
- Highlights the relationship between events
- Shows how people understand their lives – meaning

• Emerging idea
• It’s not about one or the other
• It’s about listening – really listening
• Understanding patterns as context for having a conversation with an individual about their unique experiences, beliefs and needs
I’ve never had a problem ...
When I came out I was working in a very non-judgmental [workplace]. I think that eased the actual transition of admitting to myself that I was gay. And from there I never really had a great problem. ... I haven’t had mental health problems. But I understand how debilitating depression and other mental health problems can be. I would say I’ve had some down periods which you may not class as medically depressed but you either work through it or a friend helps you through it.

(No Need to Straighten Up, Cliff, gay man)
I was really devastated and never realised the grieving process was so painful – to the point of almost physically feeling pain. Suddenly I was all alone in this empty house. Like everyone else I’ve had losses and problems but previous experiences hadn’t equipped me for this trauma. You can’t put a time on the grieving process, but the first 12 months were very hard. ....

I was a bit upset with his family because the minute he died that same week they were there with a piece of paper saying that we want half of his possessions. ...

(No Need to Straighten Up, Cliff, gay man)
Well, if I've been discriminated against I'm not sure when
(No Need to Straighten Up: Amanda, Lesbian).
...I was never out at work, because I was in the Catholic system as a teacher. I would never have my photo taken at lesbian events until I retired. It probably wasn't a wise thing to do, to be out as a teacher in the Catholic system. Quite possibly you could have lost your job. It just was never an issue and I just never, ever talked about it. So, in that sense I don't think I faced discrimination at work.
(No Need to Straighten Up: Amanda, lesbian).
..it's been a good experience here. There's been no issues. ...The good people here made my transition very smooth. I've had no issues at all.

(Participant, Trans Ageing and Aged Care Project)
...one of the old boys took a fancy to me and got himself into the bathroom one night when I was down there toileting and roughed me up a bit but we'll let that slide for now.

...we're more or less trapped in the building. ...it's like a minimum security gaol, once you get in you can't get out sort of thing. And I just like to watch television and lay on my bed and dream of the future, a future of being independent living.

(Trans Ageing and Aged Care Project)
….. everybody just accepts the situation. ...
we've just been accepted that we're two guys living together
(LGBTI Dementia Project: Kelvin and Greg)
We have quite a few lesbian neighbours ... I think it's important because, again, you can freely [speak] ... when you're mixing with your own type, if you, like you speak freer..

(LGBTI Dementia Project: Kelvin and Greg)
Factors might contribute to the complexity of these plots:

Onus of responsibility
Onus & the shaping of narrative plots

1) Onus of responsibility to conform
2) Lowered expectations of others
3) Sense of responsibility persists
4) Shaping narrative plots – perhaps challenges are reconceptualised?
5) What does this mean for how we listen?
6) What does this mean for the services we provide?
The type to flaunt

[we] have never been the type to flaunt our sexuality...when I see people that do I would think I’d say to myself, I’m glad I’m not them....I am glad because I don’t want myself exploited, I don’t exhibit myself....when you flaunt you are embarrassing yourself (LGBTI Dementia project: Kevin, 75, gay man).

I think George and I have been lucky because we are not outrageously gay...we’re not really outrageous and not very camp in our actions... There’s a lot of people that are and they are the ones that are going to find a lot of discrimination I think...George and I are pretty straight gays if you know what I mean, not flamboyant or you’re not kind of putting it in people’s faces... I think that’s why we fit into a lot of the norm. If George was a bit more camp...someone would probably says ‘are you one of those poofers?’ (Dementia project: Nick, 54, gay man)
[We] make it easier for people, you know, not to consider it too much of an issue...a person who doesn't draw too much attention to themselves is not going to be as upsetting as a lesbian who...has an obvious male look about them (Dementia project: Anne, 60, lesbian).

I guess the women that talk the loudest about being discriminated against, ...are often stridently feminist, stridently lesbian and who almost spend their life challenging people to discriminate against them because they are lesbian. I don't know whether that sounds mean on my part or not. But I mean do you know the sort of women that. It's that: I'm a lesbian, what are you going to do about it? So, perhaps I'm too easy - you know. I'm quite easy going and I'm very flexible. I'm sure that things like that make you much more resilient. (No Need to Straighten Up: Amanda, lesbian).
Thick skin

Discrimination bounces off me ... I'm not going to scream discrimination ... for the simple reason that I look on it more as I should be educating them to what is happening. ...Well, I could have been screaming discrimination for many years. ... I think that thickened my skin ...[With screaming] discrimination, if you're not careful, I think can put you in a worse situation than it was before.

I think some people jump up and down and in doing so they're drawing attention to themselves. I look on things that I've always tried to practice the idea that I will forgive people, [others] work themselves into a hissy fit and in actual fact they make it worse for themselves.
(No Need to Straighten Up: Kathy, trans woman)
So, what have we learned about empowering older LGBTI people as self advocates?
Narrative plots - implications

1) Aged care service providers:
   • Build rapport
   • Listen carefully
   • Collective – individual
   • Disclosing ‘all’ needs (rather than just LGBTIness)
   • Narrative as foundation for CDC

2) Assessors – building rapport
3) Advocacy – absence of complaints ≠ absence of problems/needs
4) Researchers: listening methods
5) Gov/Policy Makers: creating spaces for older LGBTI people to share narratives with complex plots
6) Val’s Café: further exploration & feedback from older LGBTI people
For more information …